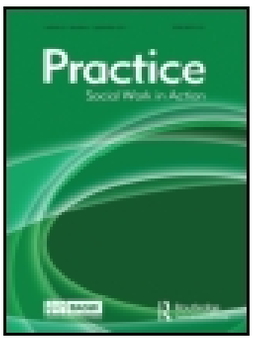

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Emma Wakeman & Nicola Moran

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The Missing Voices: Carers' Experiences of Section 17 Leave (Mental Health Act 1983) in England

Emma Wakeman and Nicola Moran

In the United Kingdom, 1.5 m partners, friends and family members provide substantial care and support to people experiencing mental health problems. Previous studies have focused on the experiences of such carers in community settings. This study focused on carers of those detained in inpatient settings under the Mental Health Act 1983 who maintain relationships via Section 17 (s.17) leave. Semi-structured telephone interviews with five carers were analysed thematically and identified that carers: struggled with the emotional impact of s.17 leave, experiencing anxiety, guilt, and stigma; experienced practical challenges and self-sacrificed in order to support s.17 leave; but reported positive impacts on the maintenance and development of their and the detained person's social identities and networks. However, these carers received very little support. Implications for social workers include the need to support carers before, during and after s.17 leave, through supporting their involvement in planning the leave, ensuring that escorted leave is staffed by those known to the carer, raising awareness of carer needs and referring carers for support and/or psychoeducation and a care needs assessment. Social workers are well-placed to take a holistic view and support carers in navigating the challenges that caring for somebody around s.17 leave can bring.

Keywords: carers; mental health; section 17 leave; Mental Health Act; detained

Introduction

An estimated 1.5 m partners, friends and family members provide substantial support to people experiencing mental health problems (Carers Trust 2019). In this paper, the term carer will be used to encompass all these relationships. The Triangle of Care guidance, developed in 2010 by Carers Trust in partnership with carers, highlights the importance of including carers (alongside service users and

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practitioners) in care, support and decision-making for those with mental health conditions (Worthington, Rooney, and Hannan 2013). However, of those who wanted friends or family involved, only half of service users reported that mental health services included carers in their care and support planning (Care Quality Commission 2018), which is contrary to policy (Department of Health 2008) and guidance (National Institute for Health and Care Excellence (NICE), 2011).

Carers' needs are perhaps least likely to be considered when the person they care for is admitted to a mental health hospital. Yet, with 49,988 new detentions recorded in 2018/2019 (NHS Digital 2019), not including those already detained, this is a significant group of carers. Section 17 of the Mental Health Act 1983 (s.17) allows the Responsible Clinician to grant a leave of absence from hospital from a few hours to several days, enabling detained individuals to spend time with family or friends. This leave can be escorted or unescorted depending on the need and risk assessment of the person detained. S.17 leave is useful for both short and long-stay hospital patients to maintain social relationships and/or for testing out readiness for discharge. Good practice dictates that planning for discharge should begin at the start of the admission and involve carers (Department of Health 2008; NICE, 2011). In determining whether s.17 leave might be appropriate to support with discharge, the responsible clinician should consider if the individual could have access to support from family, friends or formal carers. With a rapid turnover in bed occupancy, and moves towards early discharge, there are concerns that this determination frequently does not take into account carers' willingness or ability to provide this support and furthermore that carers are not fully involved in decisions about s.17 leave (Giacco et al. 2017) whether for the purpose of temporary leave from hospital or to support with discharge.

Recovery from mental health problems is aided by a perceived connectedness to others and a meaningful social identity (Tew et al. 2012; Corrigan and Phelan 2004). This is especially important as those who encounter mental health problems often experience shame, ostracisation from social groups, and blame for their ill health (Thornicroft et al. 2016). However, mental health services have been criticised for ignoring social interventions that aim to improve the social networks of those with mental health problems (Webber and Fendt-Newlin 2017). People detained under the MHA are often removed from their familiar social support systems through being detained out of area, restricted to infrequent visits from family, or lengthy detention. S.17 leave is one way that detained people can receive social support and maintain active membership of their support network, irrespective of where the hospital is located. Accessing social networks enables people to build social capital (Lin and Erickson 2008), which can benefit people with mental health issues by improving their social status and feelings of empowerment which in turn can lead to a sense of positive self-worth and purpose (Webber et al. 2015). Even, or perhaps especially, where individuals are detained in hospital, there is a need for effective and fruitful leave with carers to contribute to recovery.

Under the Care Act 2014 carers' needs must be assessed and appropriate support provided; however, this takes time and is unlikely to include situations in which decisions are made quickly, such as when s.17 leave is requested and authorised. S.17 leave has the potential to interrupt elements of carer well-being, for example control over day-to-day life and participation in work and leisure, if s.17 leave is authorised at short notice leaving carers to cancel or change plans or appointments and/or potentially take time off work with very little notice in order to care for the patient during the period of their leave. Previous studies have identified that carers feel professionals do not involve them in decision-making, yet expect them to provide support on discharge (Jankovic et al. 2011; Wilkinson and McAndrew 2008).

Most carers studies focus on carers of older and disabled family members who live with them or close by and who provide often substantial amounts of care (Carers UK 2015; Arksey and Glendinning 2008). Research into the experiences of such carers evidences that caring can have a significant impact on physical health, emotional and mental wellbeing, and finances (Carers UK 2015; Arksey and Glendinning 2008). Some carers report mental health issues, most notably depression and emotional stress, as a result of caring (Shah, Wadoo, and Latoo 2010). However, in discussions about carers and the impact this role can have on them, carers of people detained under the MHA are under-represented and their voices are missing from the narrative.

Whilst there exists some research exploring the perspectives of carers of people in mental health hospitals (Giacco et al. 2017; Wood et al. 2013; Lloyd-Evans et al. 2010; Stanbridge, Burbach, and Leftwich 2009), there is currently no published research on approaches to improve the support provided to carers around s.17 leave. The current study thus asked: 'What are the experiences of Section 17 leave for the carers of those detained under the Mental Health Act 1983?'

Methods

Design

This qualitative study used semi-structured interviews to explore the experience of s.17 leave from the viewpoint of carers. This method enabled an in-depth exploration of the views and experiences of carers, offering a series of core questions with scope for participants to raise further issues felt to be important (Taylor, Bogdan, and DeVault 2015). Interviews were conducted by telephone. The research was based at a private hospital in England which could admit detained people from a large geographical area and thus carers often lived a substantial distance away making face-to-face interviews impractical. Although telephone interviews tend to be shorter than face-to-face interviews there is evidence that they produce rich descriptive data (Irvine

2011). Further, telephone interviews can reduce anxiety for participants as they do not have to travel to the interview or have a researcher come into their home. It was anticipated that by being interviewed without the researcher in the room, in a place they feel comfortable, participants may be more likely to share detailed accounts of their experiences of s.17 leave (Trier-Bieniek 2012), whilst acknowledging the potential disadvantages of telephone interviews including the lack of non-verbal cues such as facial expressions and body language which can change how something is perceived (King and Horrocks 2010).

Eligibility

Carers were defined as family members, partners, or friends who provided care and support for the detained person. Carers were eligible to take part in the study if the person they cared for was detained in the hospital under the Mental Health Act 1983 and had experienced s.17 leave within the last six months, and both carer and detained person were over the age of 18. Within the organisation hospital social workers have the most contact with carers and thus were sent an email asking them to identify carers who met the criteria from their caseloads and to send them a project information sheet. In addition, the researcher attended a carers' meeting at the hospital and provided an information sheet to all those present. The aim was to recruit five to eight carers.

Ethical Considerations

The information sheet clearly stated the researcher's contact details and potential participants were asked to make contact if they had any questions or wanted to volunteer to take part. This recruitment method ensured that the anonymity of the participants was protected. The information sheet also assured recipients that whether they chose to take part in the research or not would have no impact on the care and treatment of the person detained or on their own relationship with the hospital, and that their data would be kept confidential and anonymous. The researcher was a social worker within the same organisation, but undertaking the research as part of her Master's degree in Social Work Practice. Carers of people detained on the researcher's ward were excluded from the study owing to a potential conflict of interest. Ethical approval was granted by the sponsoring University (ref: SPSW/MTA/2018/10) and the organisation's research department (ref: 106).

Procedure

Once carers contacted the researcher to express their interest, the researcher made contact and discussed the study with them further. Those willing to participate were sent a consent form to complete and return by email or post and a date and time was arranged for the interview. Interviews, lasting up to one hour, were audio-recorded with consent taken again at the start of the call. At the end of the interview participants were debriefed by the researcher, who is also a qualified mental health social worker, and provided with contact details for national helpline numbers in case of distress. Audio recordings were transcribed verbatim by a professional organisation, names were replaced with pseudonyms and participant identification numbers were used to uphold anonymity and confidentiality.

Analysis

Transcripts were analysed using thematic analysis as this allowed the researcher to analyse the data without a preconceived framework or theory in mind (Ritchie and Lewis 2003). Transcripts were read and re-read until the researcher was immersed in the data. Transcripts were coded in Microsoft Word following an iterative process of initial coding, identification of themes within and across transcripts, refining of the codes and subsequent re-coding. A sample of the transcripts was coded by the second author to minimise bias, and to confirm that themes had not been missed and were reported in line with participant report. There was a high degree of congruence between both researchers' codes and the final agreed set of codes was used to re-code all transcripts. A table of themes and sub-themes arising from the interviews formed the basis for writing up the results.

Results

The Sample

Five carers took part in this research: four female and one male; four lived over 100 miles away from the hospital; four participants were a parent of the person detained and one was a sibling. Participants had experience of their detained family member being on s.17 leave over a period of 3-14 years, thus all were carers of long-stay patients. Whilst the carers' experiences of the s.17 leave varied, all had experienced providing care during visits to their family member in a hospital setting (for example, a couple of hours in the hospital grounds), leave locally to the hospital (for example, going to nearby

shops or for walks in the local area), and leave to the carer's home (potentially for a few nights or week).

Findings

Four key themes were identified from the analysis and are presented in order of what emerged most strongly: emotional impact, maintaining social identities and networks, practicalities and self-sacrifice, and professional and organisational context.

Emotional Impact

The most prominent theme, littered throughout each interview, was the emotional impact of s.17 leave on carers. Carers reported the emotional toll that s.17 leave could have on them in the form of mental exhaustion, guilt, sadness, and anxiety:

> I think I may have previously underestimated how exhausting I find it. I think this is partly because we can never be sure of what mental state he is in when we see him and partly because the journey is arduous to say the least. (Participant 2)

It was apparent from all interviews that carers' experience of s.17 leave was heavily influenced by the experience of the person detained. For example, one participant commented:

> It was a good day because [patient] was mostly OK…. I mean that's what it's all about. If she hasn't had a good time, I don't, you know and if she has then so have I. (Participant 4)

All positive or negative carer experiences of s.17 leave were impacted by their family member having a good or bad experience. This reinforces the emotional impact of the leave on the carer.

Within this theme carers also spoke about the lack of emotional support available to them. Carers appreciated the support that was offered to their detained family member but reported that there was no emotional support for themselves:

> You know, [patient] goes back to the ward and gets some support after the visit but I feel like I'm just left in limbo. I mean I get that the staff can't be there for me as that's not their role but you know, who is there? (Participant 4)

This resulted in some carers feeling isolated without an outlet for the negative emotions that arose before, during and after s.17 leave. Carers who had

good support networks reported turning to them for extra emotional and practical support. However, some carers reported experiencing stigma from family, friends or neighbours, not overtly because their family member had mental health problems but because they were 'detained'. In part this was explained as people confusing detention under the Mental Health Act with detention in prison and hence assuming a criminal element to the detention:

> I don't think they fully understand it. And sometimes I feel they talk about her, you know, in the same way you do someone who's broken … you know a criminal. I mean she's not … she's never done anything like. (Participant 4)

Some participants felt that this reflected a lack of understanding of mental health and the law in their wider communities. A couple of participants mentioned that their social groups consisted of other people in similar situations:

> Being a carer can be quite a lonely place to be and, you know, to, to have the chance to meet with other carers … I find that very helpful, personally, that you just don't feel as alone and you can sometimes help other people, which then makes you feel a bit better about yourself. (Participant 3)

This implies that acceptance and compassion for carers who have a partner, friend or family member detained is not necessarily widespread in society, or even within extended families or communities, and rather must be sought in groups of other carers in similar predicaments.

Carers often had little notice of when leave was going to take place which they found stressful and which made it difficult for them to prepare for the visit of their family member, for example buying in their favourite food or arranging time off work during the leave to care for them. Participants also reported that the short notice meant they were not prepared emotionally and were not aware of the emotional state of their family member:

> I more was sort of stressed because I don't know how my son is going to react, you know, sometimes he's in a good mood, sometimes he's in a bad mood. (Participant 1)

This uncertainty about the mood or state of the detained family member meant there was an air of unpredictability as to what would happen during the leave, which could create further anxiety for carers.

Maintaining Social Identities and Networks

It was clear from the interviews that s.17 leave supported relationships. Without s.17 leave carers argued they would not have continuing relationships with their family member as many of the mental health conditions of the people detained meant that face-to-face contact was the most productive, or indeed only, way to continue to build such relationships:

> If it wasn't for those visits we would have virtually no contact with him at all. I've tried writing letters; they just get left unopened (Participant 3)

S.17 leave gave carers and their wider family the opportunity to willingly continue with their social identities such as parent or sibling. Carers were eager for these identities not to be muted or cut whilst their family member was in hospital and also spoke of how s.17 leave enabled wider family meetings which were deemed especially necessary as family members were detained far away and for long periods of time and thus could only reconnect with extended family on longer home visits.

In addition, carers talked about how it was vital both for themselves and for their detained family member to maintain the social networks and identities that were in place before the detention. It wasn't just seeing their family member that was important to carers but also to engage in dialogue and activities that had been meaningful to both parties throughout the relationship.

> As a youngster, he would sail with us and with his school and, you know, sailing was something that he did … we took him sailing [whilst on s.17 leave] and it was like a light had come on inside him and he started to become, and this is sort of a really positive thing about it, so much more receptive to the treatments. (Participant 3)

Carers also saw importance in a detained family member having connections to community networks which would help with their continuing recovery when they were discharged. Many carers wanted to utilise s.17 leave to help their family member continue with activities they used to enjoy before they were detained or to build new social connections outside of a hospital setting.

Although S17 leave can be unescorted, participants in this research stated that during the period of s.17 leave their family member was accompanied by a member of hospital staff, for support, observation, to ensure medication compliance, and to guard against absconding. Staff support and the way they conducted themselves were key to positive experiences for carers as their presence could impact on the social identities they were keen to uphold and acceptance of the carer and family member into wider social networks. Carers expressed a preference for their detained family member to be accompanied by staff they already knew as this made the inclusion of the staff member in family environments more comfortable and meant a degree of trust was already in place:

> We had two staff members here, one of whom I know quite well because I've chatted to her a lot over the time he's [family member's] been there. And the other one is a guy who takes him out … So they were a great pair to have and, to be honest with you, I couldn't have asked for better. They made their presence felt in the right way; they were unobtrusive. (Participant 3)

Carers reported that it was important for staff to be present but not intrusive during periods of leave, and this was something they felt was easier if staff and carers knew each other well.

Practicalities and Self-Sacrifice

Participants discussed the practical challenges that existed for carers around s.17 leave, including financial difficulties, the impact of their own health issues, and the length of travel to visit their detained family member as most carers in the study lived more than 100 miles from the hospital. Although the hospital would fund visits within a defined space of time, e.g. every 3 months, outside of this the financial responsibility for a visit fell to the carer. For some the costs could be significant and could include hotel accommodation, meals, and long journeys by car or public transport.

Most carers described the physical and emotional impact that the long travel to provide care during s.17 leave had on them, meaning visits were not practical on a regular basis. However, this in turn left carers feeling a sense of guilt that these restrictions existed:

> It's really hard for me to you know get and see her you know but I think… I feel like I have to as it's good for her… I don't really think about myself while I'm there. (Participant 4)

This led to some carers self-sacrificing, for example allocating more resources than they could afford to support the s.17 leave and/or putting their practical and emotional needs to one side in order to care for their detained family member during s.17 leave.

Professional and Organisational Context

Carers' experiences of supporting their detained family member during s.17 leave were influenced by the organisational context. Some carers did not feel involved in decisions around s.17 leave such as the timing of the leave or where their family member could go. Carers commented that this could leave them feeling powerless. Although carers acknowledged that organisations and professionals had to have certain procedures for risk management, they described how this could leave them feeling unimportant and their opinions undervalued:

> But they're the rules and we have to go by them… he's been on section for so long that we've just come to accept everything as being normal. (Participant 2)

This wasn't the case for all carers with some discussing times that they had made suggestions that were taken on board and executed successfully for s.17 leave.

Some participants offered suggestions as to how s.17 leave could be improved for carers. All carers in the study lived many miles away from the hospital and thus had no knowledge of the local area or where to take their

detained family member if the s.17 leave had to take place locally to the hospital. Two carers suggested that access to information about local activities would be helpful, for example opening and closing times and prices for local places. In addition, improved emotional support for carers was felt to be vital:

> I think someone should contact the carer and say, 'How did it go? What did you feel? Are you OK now?' and 'What can we do to make things better?' It was left up to me to contact the social worker, say it was a bad visit. (Participant 1)

Where this support came from, either the organisation where their family member was detained or the local authority/NHS trust in the home area, carers were not sure but most suggested a need for improvement in this area.

Discussion

The findings explore the impact on carers when a person they care for experiences s.17 leave. They help to give a voice – the missing voice – to those carers who are rarely the focus of such research. Carers described both positive and negative experiences but it was clear that overall s.17 leave was wanted and was often the only way to continue their relationship with their detained family member, and help maintain their familial and social identities and connections within the community. Social connections, social capital and positive social support for those with mental health problems have been identified as key elements in a person's recovery (Corrigan and Phelan 2004; Tew et al. 2012; Webber et al. 2015) and the carers in this study also felt this to be important. By engaging in s.17 leave carers felt they were able to help their detained family member build social capital, something that would be beneficial in terms of resources and status when they re-joined their community following discharge from hospital.

However, this often came at a price of self-sacrifice and an impact on the carer's emotional well-being. Carers were often informed of s.17 leave at short notice which heightened stress and anxiety around being prepared for the visit (emotionally and practically, including arranging time off from work to care for their family member). The interdependence of mood between the carer and patient meant that carers reported being on edge as they did not know what mood or mental state their family member would be in during the visit. It was the experience (positive or negative) of the patient that determined how the carer themselves experienced the leave. Carers also reported a financial impact of s.17 leave which often led to limitations on how often they could see their family member, and this in turn could add to the emotional burden with carers reporting feeling guilty about not being able to visit more frequently. These findings reflect those of a study undertaken by Carers

UK (2015) with carers in the community. In both studies, carers stated that they put their partner, friend or family member's needs first but the consequence of this was that their own needs and physical, financial, emotional and mental health suffered.

The findings also suggested that the detaining organisation holds a lot of power, with carers sometimes feeling powerless and undervalued. Whilst carers agreed this power imbalance might be necessary to allow the organisation to care for and treat their detained family member, they felt there was room for improvement. It can be difficult for carers when the person they care for enters a new system and the carers' opinions and input is no longer seen as having the most value (Lloyd-Evans et al. 2010). The Triangle of Care (Worthington, Rooney, and Hannan 2013) encourages organisations to include carers and to see the value they can contribute to the care and treatment of those with mental health conditions. If the Triangle of Care, or at least its ethos, was woven into practice across mental health services then carer input may be encouraged and this in turn might help to redress some of the power imbalance that carers reported. For example, staff training programmes focusing on the inclusion of families in inpatient mental health services have shown some positive results (Stanbridge, Burbach, and Leftwich 2009).

Carers reported a high emotional impact of s.17 leave but no or little professional emotional support. Emotional support may be available from other family members or friends, but some carers are socially isolated and others reported experiencing stigma from family and community due to having a family member detained. Carers suggested it would be helpful for them to be contacted following s.17 leave for a debrief. Small changes such as trying to make sure familiar staff accompany their family member on s.17 leave or regular contact with carers to offer emotional support could go a long way to improving carers' experiences.

The Care Act 2014 and rights of carers to have assessments of their own needs applies only to carers involved on a day-to-day basis with the person they are caring for and thus does not apply to carers of people who are detained (Carers UK 2014). The spectrum of carers' needs and rights, for example around s.17 leave and access to emotional support, was outside the scope of the recent review of the Mental Health Act (Wessely et al. 2018). There seems to be a need for carers of people detained to receive structured emotional and practical support and currently this is not commonplace. Resources for mental health services are stretched, however providing support to carers of those detained would be beneficial in the long-run. It could reduce the risk of carers burning out or needing mental health services themselves, something that is evidenced to be a risk for carers (Carers UK 2015). Carers of those detained would not need as much input as those who have day-to-day contact with the person they care for, however providing carers with regular emotional and practical support could also help with the stigma some carers feel by having a relative with a mental health problem who is also detained.

Additionally, if carers and patients can engage in mutually enjoyable s.17 leave this could contribute to patients' recovery. This would have a positive human and economic impact by reducing the time a person spends in hospital. Furthermore, practical support such as funding to support carer travel expenses when they must travel long distances for s.17 leave could help reduce guilt and anxiety and financial challenges. This would be especially beneficial where patients are detained out-of-area.

Limitations

The study findings are based on a small sample and thus cannot be generalised. Future research could try to recruit a larger and more diverse sample, including carers with different relationships to the detained person, carers of those detained for short periods of time, carers of those detained locally, and carers of detained patients from BAME backgrounds who are more likely to be detained under the Mental Health Act 1983 (GOV.UK 2017), as some of the issues may differ. Finally, the research was conducted in one hospital setting (a private hospital); future research could incorporate different types of setting (including NHS Trusts) and explore how, if at all, carers' support and experiences of s.17 leave differ. Implications for policy and practice must be considered in the context of the study limitations.

Implications for Policy and Practice

Implications for social workers include the need to recognise and support carers before, during and after s.17 leave. This could be a role for hospital social workers who could work to ensure that carers are involved in decision-making and planning around s.17 leave, that where leave is escorted the staff are known to (and ideally have good relationships with) the patient and carer, provide or arrange support around the leave, help to raise awareness of carer needs within multi-disciplinary teams, and refer carers to carer support and/or psychoeducation groups and for Care Act assessments. Community-based social workers could provide carer support in the home local authority/Trust, in particular where carers have care and support needs outside of s.17 leave and/or where patients are detained for short periods of time and/or are detained far from where the carer lives. Whilst the role of carer lead and/or carer champion are not necessarily 'social work roles', social workers are well placed to take a holistic view and help carers navigate some of the emotional, practical and financial challenges that caring for somebody during s.17 leave can bring. Further, social work education and training could include a focus on the support needs of carers of people with mental health problems, including their needs if the person they care for is admitted to hospital and especially if

they are detained under the Mental Health Act and may be granted s.17 leave. Working to the principles of the Triangle of Care, which emphasise the three-way relationship between patients, carers and mental health professionals, could further strengthen the inclusion of, and support for, carers. Such issues could be addressed in a future review of the Care Act.

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ORCID

Nicola Moran http://orcid.org/0000-0002-6219-0394

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Emma Wakeman is a Senior Social Worker in a neuropsychiatry setting at a psychiatric hospital. Her role involves supporting patients and also working with the carers of those detained.

Dr Nicola Moran is a Research Fellow at the University of York with research interests in mental health social work, carers, and the intersection of mental health and criminal justice. Email: Nicola.Moran@york.ac.uk